



STATE OF HAWAII
DEPARTMENT OF HEALTH
FAMILY HEALTH SERVICES DIVISION
CHILDREN WITH SPECIAL HEALTH NEEDS BRANCH
741 SUNSET AVENUE
HONOLULU, HAWAII 96816

May 30, 2006

TO: Physicians, Health Care Providers, Birthing Facilities and Laboratories
Involved with Newborn Metabolic Screening

FROM: Christine Matsumoto, R.N., M.P.H. *mm*
Newborn Metabolic Screening Program Coordinator

ALERT

**Newborn Screening Testing on Children Older Than Six (6) Months of Age
Discontinued by Oregon State Public Health Laboratory**

Effective May 1, 2006, Hawaii's contracted newborn screening testing laboratory, the Oregon State Public Health Laboratory (OSPHL), will no longer test initial newborn screening specimens on children older than six (6) months of age. OSPHL has decided that the initial newborn screening testing is designed for newborns, defined as "0 to 6 months of age". Their standards and cutoffs are tailored to this age group and are not applicable to older infants and children. They are concerned about the reliability of the results and feel that it is not appropriate to accept initial newborn screening specimens for children older than six months of age.

There are private laboratories that can do newborn screening testing on children older than six months of age. See attached lists of recommended laboratories that could also be used. Newborn screening specimens on children older than six months of age need to be collected on a specimen collection form that is specific to the laboratory which will be used. **OSPHL's specimen collection form cannot be used for the private labs.** The Newborn Metabolic Screening Program (NBMSP) will not pay for this private testing, and will not be responsible for the follow-up of these screening results.

If you have any questions, please call Chris Matsumoto, Newborn Metabolic Screening Program Coordinator, at (808) 733-9069. Thank you.

NORTHWEST REGIONAL NEWBORN SCREENING PROGRAM

TESTING CHILDREN OLDER THAN SIX MONTHS OF AGE FOR NEWBORN SCREENING DISORDERS

The Northwest Regional Newborn Screening Laboratory's testing is designed for newborns, which have been defined as "zero to six months of age". Our standards and cutoffs are tailored to this age group and are not applicable to older infants and children. Thus, we are concerned about the reliability of results and feel it is not appropriate to accept specimens for children older than six months of age.

We highly recommend proceeding directly to definitive testing if there are signs or symptoms of a metabolic disorder present in the child.

Listed below is a metabolic laboratory we would recommend to provide Tandem Mass Spectrometry (MSMS) testing on older children. Also listed, are recommendations for further diagnostic testing for the other disorders on the newborn screening battery*.

MSMS Testing (AKA Expanded or Supplemental Newborn Screening) this includes testing for selected amino acid, fatty acid, organic acid and urea cycle disorders:

Baylor University Medical Center at Dallas
200 First Street SW
Dallas, Texas 75226
Telephone: 214-820-2822

Biotinidase Deficiency:
Biotinidase enzyme assay

Biochemical Genetics Laboratory
University of Maryland, School of Medicine
Division of Human Genetics
BRB 11-047, 665 West Baltimore Street
Baltimore, Maryland 21201
Telephone: 410-706-2810

Congenital Hypothyroidism:
Serum - Free T4, TSH
Can be done at most local laboratories

Sickle Cell Disease:
Isoelectric Focusing/High Performance Liquid Chromatography
Can be done at most local laboratories

Galactosemia:
Galactose-1-Phosphate
Galactose-1-Phosphate Uridyl Transferase

University Children's Genetic Laboratory
116 East Broadway
Glendale, CA 91205
Telephone: (818) 548-0999
FAX: (818) 548-1555

Congenital Adrenal Hyperplasia:
Serum - 17-OH-Progesterone
Can be done at most local laboratories

*These laboratories are listed for your convenience only. You may send your specimen to any accredited laboratory that provides the appropriate testing.

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TESTING CHILDREN OLDER THAN SIX MONTHS OF AGE
FOR NEWBORN SCREENING DISORDERS

Other laboratories that can offer expanded newborn screening testing are:

- 1) Pediatrix
 P.O. Box 219
 Bridgeville, Pennsylvania 15017
 Toll free number in the U.S. 1-866-463-6436
 www.pediatrixscreening.com

Fatty Acid Oxidation Disorders
Organic Acid Disorders
Amino Acid Disorders
Urea Cycle Disorders
Biotinidase Deficiency
Galactosemia
Congenital Adrenal Hyperplasia
Sickle Cell and Other Hemoglobinopathies
Glucose-6-Phosphate Dehydrogenase Deficiency
Congenital Hypothyroidism (not valid after 2 months of age)
Cystic Fibrosis (not valid after 3 months of age)

- 2) Mayo Medical Laboratories
 200 1st Street SW
 Rochester, MN 55905-0001
 Toll free number in the U.S. 1-800-533-1710
 www.mayoreferenceservices.org

Fatty Acid Oxidation Disorders
Organic Acid Disorders
Amino Acid Disorders
Urea Cycle Disorders